



The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Department of Public Health
250 Washington Street, Boston, MA 02108-4619

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Tel: 617-624-6000
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Dear Practice Manager, Neurologist, or Keeper of Medical Records:

This letter serves as the Massachusetts Department of Public Health's (DPH) annual request for Amyotrophic Lateral Sclerosis (ALS) cases. We sincerely appreciate the past and future cooperation of all neurologists and health care facilities statewide in reporting all patients having been evaluated for or diagnosed with ALS.

As you are aware, clinical research and interventions are often limited by incomplete epidemiologic data. Further, important public health questions have been raised regarding the possible increases in incidence of ALS. The DPH ALS Registry addresses this need for improved monitoring and is a valuable resource for the community of patients, providers, researchers, and others concerned with ALS throughout the Commonwealth.

DPH is requesting that you report any patients who have been evaluated for or diagnosed with ALS and who visited your facility between January 1, 2016 and December 31, 2016. If you are a *practice manager* reporting on behalf of the entire neurology group, please include a list of neurologists in your department or practice as well. Included are the ICD-9 and ICD-10 codes for ALS and associated illnesses that we are asking your office to report (reverse page). Upon receipt of this information, we will contact your office for an appointment to access the patients' medical records to abstract relevant patient and diagnostic information. The original records will not leave your office and we will make every effort to be as unobtrusive as possible when abstracting this information. Please return the Report Form **as soon as possible** to:

**Vanna Abille
Massachusetts Department of Public Health
Bureau of Environmental Health
250 Washington Street, 7th Floor
Boston, MA 02108**

The Massachusetts ALS Registry, as established by Section 26 of Chapter 140 of the Acts of 2003, is conducted in accordance with state law. DPH regulation 105 CMR 300.192 authorizes DPH to collect medical records and other identifiable information from health care providers on individuals diagnosed with or evaluated for ALS, which allows covered entities under the Health Insurance Portability and Accountability Act (HIPAA) to disclose protected health information to DPH without obtaining written authorization of the data subject. Additionally, under Massachusetts General Laws Chapter 111, all information collected is strictly confidential and

anyone providing information to DPH as part of this surveillance will not be liable for any damages related to the disclosure.

If you have any questions, please contact Vanna Abille at 617-624-5757. We look forward to continuing our work with you in improving the understanding of ALS occurrence in the Commonwealth.

Sincerely,

Vanna Abille, MPH
ALS Registry Coordinator, Epidemiologist

CC:

Alicia Fraser, ALS Registry Director
Robert Knorr, Director, Environmental Epidemiology Program
Tom Quail, ALS Registry Clinical Coordinator

Diagnosis Codes:

- ICD-9 code 335.20: Amyotrophic Lateral Sclerosis (ALS)
- ICD-9 code 335.21: Progressive Muscular Atrophy
- ICD-9 code 335.22: Progressive Bulbar Palsy
- ICD 10 code G12. 20 - G12.29: Diagnosis of Motor Neuron Disease
- Lateral Sclerosis
- Familial Motor Neuron Disease